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ABSTRACT

Although the effectiveness of home-based, behaviorally-oriented treatment programs with the elderly and their families has been well documented, assessment of caregivers' attitudes toward those programs remains rare. To assess the relationship between outcome measures and client and principal caregiver characteristics, 21 client-caregiver dyads, participating in the Elderly Support Project, completed pre- and post-test measures and three follow-up interviews during a 24-month period. The Elderly Support Project focused on behaviorally-oriented home-based treatment of disabled elderly clients at high risk of long-term institutional care. The program was implemented through a series of intervention steps including assessment, baseline data collection, behaviorally-oriented treatment, and follow-up. An analysis of the results showed that at the first follow-up, 74 percent of the clients were still living at home (10 percent had died and 16 percent were institutionalized). At second follow-up, 75 percent of the clients were living in the community (25 percent were deceased). The caregivers' ratings of their relationship with the client, their ability to manage the client's behavior, and the client's mental status at program termination were significantly associated with placement. Client diagnosis, caregiver ratings of target problems, and whether or not the client lived with the caregiver were significantly associated with caregivers' subsequent relational satisfaction scale ratings. (BL)

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Caregiver Attitudes Toward Disabled Elderly Family Members and Institutional Placement in a Home-Based Behavioral Treatment Program

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Introduction

The effectiveness of home-based behaviorally oriented treatment with the elderly and their families has been demonstrated by several investigators (Haley, 1983; Linsk, Pinkston, & Green, 1982). While it appears that operant conditioning is effective with this population, assessment of family caregiver's attitudes toward treatment programs and their relative's behavior remains rare. Data pertaining to these attitudes are important since the outcome of intervention (e.g. delaying or eliminating the need for institutionalization of a disabled family member) can be determined by the caretaker's assessment of their ability to provide care. For example, in a study of applications to a long-term care geriatric facility, Kraus (1976) reported that 15% of the families gave as their reason the illness of a family member other than the elderly person and another 30% stated excessive burden. Similar findings by Sanford (1975, p 472) in Great Britain led him to characterize the caregiver as "... the hub around which the future of the patient revolves".

The importance of the family as a source of support is further exemplified by recent governmental estimates that 47% of all non-institutionalized elderly are limited in some way because of chronic impairment (Tobin & Kulys, 1981). Unfortunately, the literature to date on home-based care of the elderly has remained narrow and focused almost

exclusively on the disabled person. However, as the effectiveness of community based treatment programs becomes more established, clinical investigations should expand in scope to determine whether outcome is differentially associated with client and/or caregiver characteristics. Varaibles hypothesized to be associated with placement of the disabled elderly include: availability of additional support persons and maintenance of family contact (Zarit et al., 1980), Excessive levels of disruptive behavior especially aggression, delusional statements, and sleep disturbances (Crossman et al., 1981; Sanford, 1975; Grad & Sainsbury, 1968), organic brain syndrome and related disorders (Pasnau et al., 1981; Tobin & Kulys, 1981), financial resources (Lieberman, 1978; Fengler & Goodrich, 1971), caregiver's gender (Nardone, 1980; Brody, 1974), residence of caregiver vis-a-vis their elderly relative (Reifler et al., 1981), health of caregiver (Johnson & Bursk, 1977), and the caregiver's own health related disabilities (Tobin & Kulys, 1981). Therefore, the purpose of this analysis is to determine what relationship, if any, exists between outcome measures and client-caregiver characteristics.

Program Description

The primary focus of the Elderly Support Project has been the home-treatment of disabled elderly clients at high risk of long-term institutional care. The program has included procedures to ameliorate problematic behavior in

the home, usually by using reinforcement principles and shaping procedures (eg. reinforcing successive approximations of desired behaviors) to increase prosocial and adaptive behaviors.

Intervention was implemented through the following series of steps:

Step 1 - Referral

Project staff would meet with the staff of referring agencies to discuss the subject's appropriateness for the project as measured against the established criteria (Pinkston and Linsk, in press).

Step 2 - Assessment

After written permission is obtained, assessment begins with a in-home interview. This includes identification of supportive family or concerned friends, environmental resources and personal strengths, problems, and desired outcomes.

Step 3 - Problem Definition and Collection of Baseline Data

This section of the interview is devoted to helping the family define problems in terms of behavioral excesses and deficits. The family is then engaged in an exploration around the specific problem, the desired outcomes and examples of those outcomes. Following the definition of specific targets or goals, the researcher/clinician teaches the older person, relatives, and significant others basic

data collection procedures in the home. Reliability of outcome data was established by analyzing the primary caregiver's ratings of targeted behaviors with those of a project member not directly involved with the clinical interventions.

Step 4- Behavioral Education of Support Persons

The focus of this training included the following: assessment of current behavioral knowledge; orientation to social learning theory and operant principles; and specific examples and applications of the principles and procedures through role play, modeling, feedback and discussion.

Step 5- Development of Treatment

Intervention training begins with teaching the family how to graph the baseline data points. Each graphed behavior is discussed in detail with the family and appropriate goals for the success of the program are determined. The researcher/clinician maintains graphs in order to provide constant feedback as to the effectiveness of the treatment procedures. This provides a source of reinforcement to the family for maintaining data collection and intervention behaviors. Specific interventions included: Modeling and feedback, cueing, reinforcement, and discriminative stimuli (differential reinforcement).

Step 6- Maintenance and Extension of Treatment Effects

The maintenance of treatment effects is discussed with the support persons and centers on two concepts: the

administration of appropriate antecedent stimuli and the fading of positive reinforcers. The discussion includes examples, role plays, and guided practice.

Step 7- Termination and Fading of Researcher

In ideal termination, the researcher/clinician and subject terminate after the program goals have been achieved. Once this has occured, the transfer of responsibility of the program to others and the fading of the researcher/clinician are accomplished. The major steps include: (a) stable level of targeted behaviors for at least one month, (b) support persons able to independently initiate any necessary modifications in the program, (c) the transfer of all monitoring responsibilities to the support person, (d) fading of researcher/clinician contacts from weekly to bi-weekly to monthly visits, (e) termination by researcher/clinician after two months of successful fading and maintenance of goal achievement.

Step 8- Followup

The followup instruments are administered at three and six month intervals following termination. If indicated, additional programming procedures or referrals were implemented.

Methods

Twenty-one dyads consisting of an identified client and principle caregiver comprised the present sample. Mean client age was 70.9 while the mean age of the caregivers was

60.2. Twelve (57%) of the subjects were diagnosed as having a functional disorder; nine (43%) organic. Fourteen or 66% of the caregivers were spouses; the remaining 33% being the clients' adult children or, in two instances, neighbors. Fourteen (66%) of the clients were female as were 62% of the family caregivers. In addition, seven or 33% of the cases did not have additional support persons available. Data were collected at as many as five different time points. These included: a pretest measure prior to program participation, a posttest measure at program termination, a consumer evaluation average administration time five months following program termination, and two follow-up phone interviews with mean completion times of ten and fifteen months from termination respectively.

The pre/post assessment package includes two major questionnaires : The Older Person Pre/Post Questionnaire (OPPQ) and The Relative Pre/Post Questionnaire (RPQ). These Questionnaires incorporated components of a number of standardized instruments including the OARS multidimensional assessment (Pfeiffer, 1976), The Philadelphia Geriatric Center Scales (Kleban et al., 1971), Shanas Health Inventory (1960), and the Kahn/Goldfarb Mental Status Questionnaire (Kahn et al., 1961). Pre-Tests were administered following engagement in the program and post-tests at or near termination.

The Consumer Survey was administered to all available support persons and to subjects able to respond to questions. The purpose of the survey was to measure the

client's appraisal of the program as well as determine some additional descriptive information about clients. The Survey also provided some followup data about changes in target behaviors since program termination. In addition, the Suvey was administered by a project staff member without previous contact with the family to minimize response bias. Each interview was recorded and lasted approximately one hour and was adapted from Friedman (1979).

The final phase of the program included 2 years of followup data to monitor the post-intervention activities in each case. The purpose of these followups were to : (a) Monitor changes in subject and support person situation; (b) Monitor changes in target behaviors after termination; and (c) Offer additional services if they were needed and desired. Time of followup contact ranged from 7 to 24 months following case termination.

The outcome measures identified were as follows: 1) Caregiver satisfaction with ability to manage the client's disruptive behavior, learn treatment procedures, and an overall rating of their relationship with the disabled family member; 2) Caregiver ratings of seriousness and improvement in targeted problems at pre, post, and follow-up time intervals; and 3) The living situation (eg. community, nursing home, etc.) of the client at termination and follow-up. In addition, the relevant literature was reviewed and several factors hypothesized to influence these outcome measures were also identified. These included: the caregiver's familial relation to the client, the caregiver's

age and income level, the caregiver's assessment of the client's level of medical interference and ability to perform independently tasks of daily living, the number of medications the client was using, whether additional support persons were available, and a self-rating of their general health condition. Client variables examined were age, diagnosis, mental status exam scores, and the principle caregiver's assessment of their overall physical health.

Results

Results from follow-up one (n=19) indicate that 74% of the clients were still living in the community, 10% had died, and 16% were institutionalized. Available data from follow-up two (n=14) revealed that these findings remained consistent (75% were living in the community and 25% were deceased). Statistical analysis (chi-square) of the variables hypothesized to affect living situation revealed that the caregiver's ratings of their relationship with the client and their ability to manage the client's behavior were significantly associated with placement ($x^2 = 6.18$, $p < .05$ for relationship; $x^2 = 9.23$, $p < .01$ for behavioral management). Similar results were also reported for the client's mental status score at program termination ($x^2 = 3.9$, $p < .05$). None of the other predictor variables of community-institutional placement reached significance.

Further analysis of these data, utilizing an non-orthogonal ANOVA design, revealed that client diagnosis

($F=7.8$,$p< .017$), caregiver ratings of target problems at termination ($F= 106.9$,$p< .001$), and whether the client lived with the caregiver ($F= 209.6$, $p< .001$), as well as the interactional effect of the caregiver's ratings of target problems and their residence ($F= 15.6$, $p< .026$) all were significantly associated with caregivers subsequent relational satisfaction scale ratings. A Multiple Classification Analysis of significant F scores was also performed to determine the magnitude of these effects. Finally, the covariation between the clients' and caregivers' ratings of health was found to be significant ($Rho = .58$, $p = .018$).

Discussion

In interpreting these results, it is important to note how many variables did not influence placement. Even though these families exhibited a diverse range of demographic and clinical qualities, a substanial majority (74%) were able to maintain their disabled family member in the community following program participation. A price may be exacted for this though, as family members providing care for seriously impaired elderly clients tended to also report poor health. Secondly, both satisfaction with the relationship and ability to effectively manage disruptive behavior at postest were necessary to reduce institutional placement. These factors were, in turn, differentially related to the client's diagnosis (providing care to clients with organic disorders scored higher on satisfaction scales), whether the

support person lived with the client or not (although familial relation per se was not significantly associated with outcome, caregivers who did not live with the client rated their satisfaction higher), and the caregiver's rating of the target problem's seriousness following program participation (lower ratings of seriousness were associated with higher ratings on the satisfaction scales). Interventions aimed at assisting families caring for the disabled elderly must address not only the specific behaviors creating caregiver stress but also the potential fallout these behaviors may have on the caregiver-carereceiver relationship if unnecessary institutional placement is to be avoided. Furthermore, some dyads appear to be cluster more around low levels of relational satisfaction than others and should therefore receive particular attention when attempting to engage and work with these clients. These would include dyads where the caregiver and the disabled relative live at the same residence, the disabled family member has a functional disorder, or scored poorly on the Kahn Mental Status Exam indicating excessive cognitive impairment. These data thus provide an empirical base for conceptualizing clinical effectiveness in home-based care of the disabled elderly as well as identify client and caregiver characteristics that are significantly associated with the attainment of treatment goals.

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